Chapter 8. What are the patterns of health services utilization of HIV-infected people in Massachusetts?

Chapter 8 presents information on utilization patterns of HIV-related services among HIV-infected people in Massachusetts. The description of HIV-related services in this chapter is categorized into two groups: ***primary medical care*** and ***support services***.

The challenge in presenting information about service utilization is that there is no single source of data that captures information across service areas (such as medical care, housing and prescription drugs) or across funding streams (such as the Ryan White Care Act, Medicaid or state and city funded programs). Therefore, this chapter relies on various sources of information to describe core services and, where data are available, the degree to which those services are meeting the needs of HIV-positive consumers in Massachusetts.

How many people do we expect to be receiving some HIV-related medical and/or support services in MA? (See Diagram 8.1)

- ✓ There are an estimated 21,000-23,000 people living with HIV in Massachusetts.

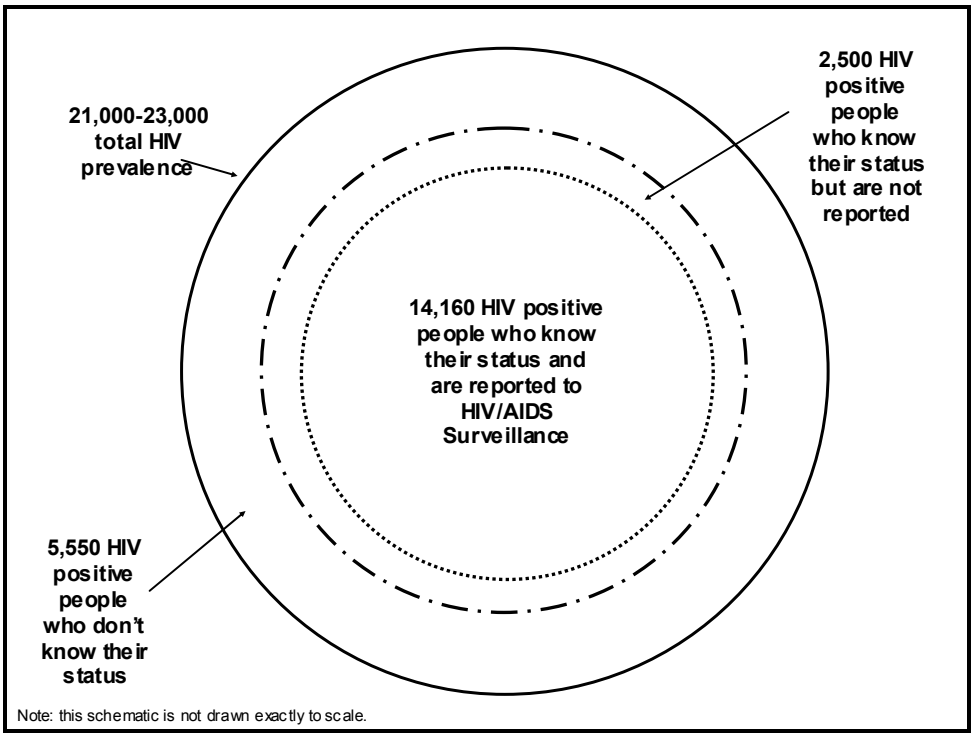
- ✓ Of these, 14,160 know they are HIV-positive, and the case has been reported to the Massachusetts HIV/AIDS Surveillance Program. Through an analysis conducted for an evaluation of the Surveillance Program, it was estimated that this number reflects approximately 85% of all people living with HIV/AIDS in Massachusetts who know their status. Applying this proportion would indicate that an estimated additional 2,500 people know they are HIV-positive but the case has not yet been reported to the Surveillance Program.

- ✓ Of the 14,160, it is expected that nearly 100% of them have had some interaction with the medical system because only a clinical care provider can submit an HIV case report form to the Surveillance Program.

- ✓ Of the estimated 2,500 not yet reported, it is also possible that some are utilizing services.

- ✓ Of the estimated 5,550 people who are HIV-positive and do not yet know their status, it is safe to assume that none are receiving HIV-specific services.

Diagram 8.1 Reported and estimated total number of people living with HIV/AIDS in MA as of July 1, 2003



Considerations for interpreting the data presented in this chapter:

- **Total number of consumers.** It is estimated that the total number of people who potentially are using HIV-related medical and/or support services in MA is **14,160**.

- **Publicly-funded services.** Data from publicly-funded medical or support services are more readily available for analysis and presentation than data from privately funded sources. Many people who are HIV-positive utilize privately funded services, in particular services paid for by individual or group private health insurance plans. It is not known how many of the estimated 14,160 consumers in MA utilize private insurance. This chapter contains data from publicly-funded sources only.

- **Degree of morbidity.** As people experience greater levels of morbidity, are less likely to be employed and less likely to have private medical insurance, their likelihood of using publicly supported services increases. For example, people with an AIDS diagnosis are more likely to use publicly-funded services, and, therefore, are more likely to be represented in these data than people with HIV (non-AIDS) or those who are asymptomatic.

In summary, data presented in this chapter are more likely to represent people who are more advanced in their disease as well as people who otherwise qualify for publicly-funded services based on income eligibility and disability. Because no single database contains all of the information for all of the services of interest, none of the data

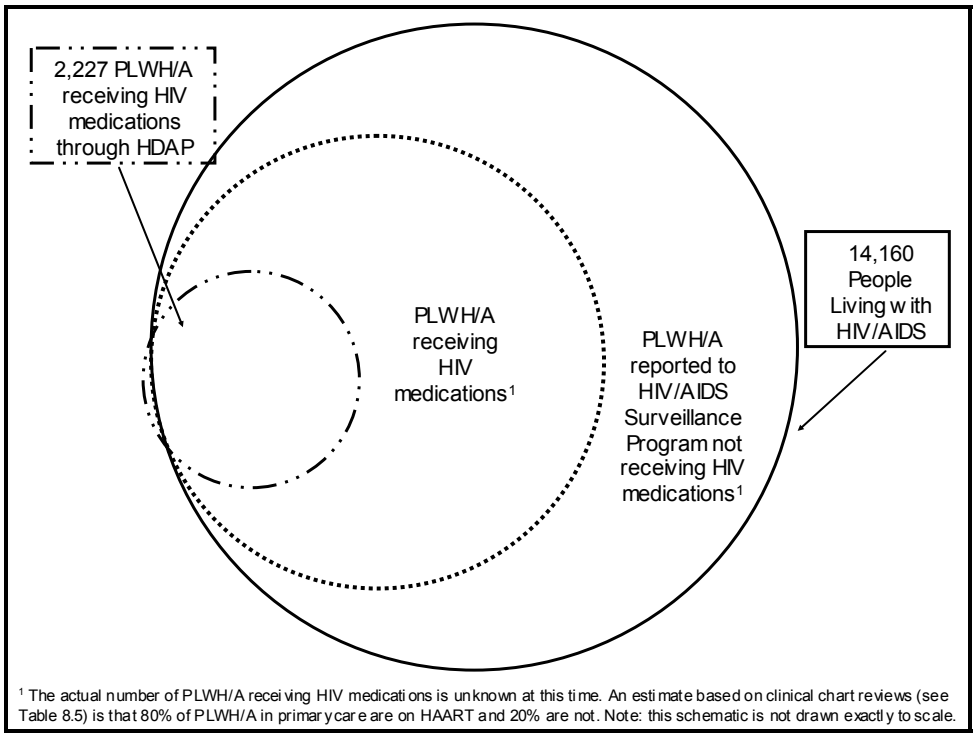
presented can be used to generalize about all people receiving HIV-related services in Massachusetts, nor about all HIV-positive people in Massachusetts. To assist with interpretation of this chapter, each section begins with a diagram to illustrate the particular population and services being described by the data in that section. Note that the diagrams are not drawn exactly to scale and are merely schematics to show the size of the population being described relative to all people reported to be living with HIV/AIDS.

Section 1. Primary Medical Care

Two sources of data will be presented to describe utilization of primary medical care services in Massachusetts: data from the HIV Drug Assistance Program (HDAP) and data from the ACT Now primary care centers.

A. HIV Drug Assistance Program (HDAP)

Diagram 8.2 People living with HIV/AIDS in MA who receive financial assistance in accessing medications through the HIV Drug Assistance Program as of July 1, 2003



- Of 14,160 people living with HIV/AIDS in MA, 2,227 are receiving medications through the HIV Drug Assistance Program (HDAP).

Table 8.1 HIV Drug Assistance Program (HDAP) Enrollees in 2002 and People Living with HIV/AIDS as of July 1, 2003 by Gender, Place of Birth, Race/Ethnicity and Exposure Mode: MA

	HDAP Enrollees		PLWH/A	
Gender:	N	%	N	%
Male	1,652	74%	10,121	71%
Female	574	26%	4,039	29%
Transgender	1	<1%	--[1]	--[1]
Place of Birth:	**N**	**%**	**N**	**%**
US	1,266	57%	10,122	71%
US Dependency	185	8%	1,776	13%
Non-US	695	31%	2,262	16%
Unknown	81	4%	0	0%
Race/Ethnicity:	**N**	**%**	**N**	**%**
White (not Latino)	869	39%	6,686	47%
Black[2]	547	25%	3,756	27%
Hispanic/Latino	479	22%	3,461	24%
Asian/Asian American	33	1%	158	1%
Native American/Aleut/Eskimo	11	<1%	18	<1%
Brazilian	88	4%	--[1]	--[1]
Other Portuguese Speakers	33	1%	--[1]	--[1]
Other/Unknown	167	7%	81	1%
Exposure Mode:	**N**	**%**	**N**	**%**
Male-to-male sex (MSM)	757	34%	4,582	32%
Injection Drug Use (IDU)	375	17%	4,397	31%
MSM/IDU	0	0%	463	3%
Heterosexual Sex	867	39%	1,925	14%
Other[3]	228	10%	220	2%
Presumed Heterosexual Sex	--	--	1,914	14%
No Identified Risk	--	--	659	5%
TOTAL	**2,227**		**14,160**	

[1] category not collected by HIV/AIDS Surveillance Program

[2] For HDAP data, the race category of "Black" actually reflects clients who report African American non-Hispanic as their race. (Black was not an option though this has recently changed to be consistent with the new federal race categories. For Surveillance data, the race category of "Black" includes Blacks of all ethnicities, except Hispanic.,

[3] Other includes pediatric, blood/blood product and occupational exposures

Data on pediatric cases of HIV infection (non-AIDS) are not indicated here; Data Source: Massachusetts HIV Drug Assistance Program, MDPH HIV/AIDS Surveillance Program (percentages may not add up to 100% due to rounding); Data as of 7/1/03

Table 8.1 is a comparison of clients served by HDAP and people living with HIV/AIDS. Because Medicaid covers the cost of medications, Medicaid recipients, who are a substantial population, do not need to use HDAP. Therefore, in comparing HDAP enrollees to people living with HIV/AIDS, one would expect some differences as people living with HIV/AIDS include Medicaid recipients (who may differ from HDAP enrollees) and HDAP enrollees do not.

- The HIV Drug Assistance Program (HDAP) is serving a slightly greater proportion of males compared with the proportion among all people living with HIV/AIDS in Massachusetts where the case was reported to the HIV/AIDS Surveillance Program.
- HDAP serves a greater proportion of non-US born people compared with the proportion of non-US born among people living with HIV/AIDS (31% vs. 16%).
- HDAP is serving a lower proportion of Whites compared with the proportion among people living with HIV/AIDS.
- HDAP serves a higher proportion of people exposed to HIV through heterosexual sex and a lower proportion of people exposed through injection drug use compared to all people living with HIV/AIDS.

Table 8.2 HIV Drug Assistance Program (HDAP) Enrollees in 2002 and People Living with HIV/AIDS as of July 1, 2003 by Health Service Region of Residence and Age: MA

	HDAP Enrollees		PLWH/A	
Health Service Region:	N	%	N	%
Boston HSR	714	32%	4,607	33%
Central HSR	154	7%	1,228	9%
Metro West HSR	316	14%	1,712	12%
Northeast HSR	380	17%	1,977	14%
Southeast HSR	404	18%	1,978	14%
Western HSR	259	12%	1,636	12%
Unknown	--	--	9	<1%
Prison[1]	--[2]	--[2]	1,013	7%
Age:	**N**	**%**	**N**	**%**
Under 13	21	1%	36	<1%
13 to 19	6	<1%	58	<1%
20 to 24	31	1%	213	2%
25 to 29	115	5%	559	4%
30 to 34	257	12%	1,508	11%
35 to 39	504	23%	2,966	21%
40 to 44	497	22%	3,428	24%
45 to 49	366	16%	2,698	19%
50+	430	19%	2,694	19%
TOTAL	**2,227**		**14,160**	

[1] HSRs are regions defined geographically to facilitate targeted health service planning. While prisons are not an HSR the prison population is presented separately in this analysis because of its unique service planning needs. Prisons include persons who were diagnosed with HIV/AIDS while in a correctional facility
Data on pediatric cases of HIV infection (non-AIDS) are not indicated here; Data Source: Massachusetts HIV Drug Assistance Program, MDPH HIV/AIDS Surveillance Program (percentages may not add up to 100% due to rounding); Data as of 7/1/03

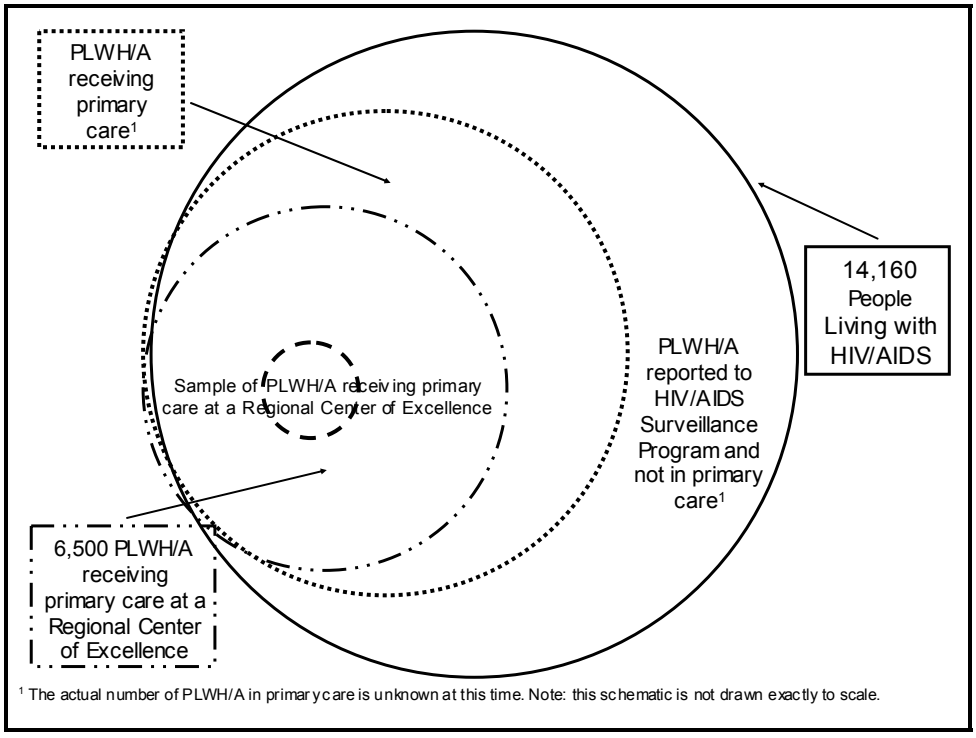
- The geographic distribution of HDAP clients by Health Service Region of residence is similar to that of people living with HIV/AIDS.

- The age distribution of HDAP clients is similar to that of people living with HIV/AIDS.

B. ACT Now Primary Care Centers

There is no single source of medical services data. Typically, medical data are maintained at a clinic or hospital setting and are gleaned from chart reviews or research activities. For this section, medical data for HIV-positive consumers are drawn from a chart review of publicly-funded clinical care sites in MA as part of an ongoing quality assurance effort. The data, which are on a sample of clients who use these services, are instructive for understanding ongoing clinical practice and the complexity of the clinical care needs of HIV-positive consumers.

Diagram 8.3 Sample of people living with HIV/AIDS and receiving clinical services from primary care centers in MA



- Of the 14,160 people known to be living with HIV/AIDS in MA, approximately 6,500 utilize one of the eighteen publicly-funded primary care Regional Centers of Excellence (Diagram 8.3). A sample of medical records of these clients was reviewed as part of the quality assurance initiative. Following is a description of this initiative and the information that was gathered.

The Massachusetts Department of Public Health (MDPH) HIV/AIDS Bureau funds clinical sites for uninsured or underinsured people living with HIV/AIDS to receive high quality medical care and other key support services; the program is called AIDS Care

and Treatment (ACT) – Now. Over the past few years, the HIV/AIDS Bureau has contracted with JSI Research and Training Institute, Inc., to create a quality assurance plan for the ACT Now sites. A collaborative approach to developing the plan has been implemented with the sites. In addition, improvements are being made to documenting clinical interactions so that the data will be more valid in the future. For example, the data in this chapter indicate that there is inadequate risk reduction counseling, but this may be due to clinicians' not recording information about risk reduction counseling in the patients' charts.

A core component of developing the quality assurance plan was the collection of baseline data in order to describe current clinical care practice. Chart abstraction was conducted by research nurses and clinical research assistants from JSI who had appropriate training and were bound by strict standards of client confidentiality. Record abstraction for HIV care information in 1999 and 2000 was completed for all 18 clinical sites affiliated with eleven ACT Now programs throughout Massachusetts. A target sample of 70 patients per clinic was chosen. The data presented here represent records of 976 patients in 1999 and 998 in 2000; nearly 70% were the same patients reviewed in both years.

The baseline data collected through abstraction of patient records include: demographics, clinical events (hospitalizations, pregnancies, co-morbidities, sexually transmitted diseases, opportunistic infections), laboratory measures, prevention education and counseling, screening, immunizations, prophylaxis, medications (for HIV and mental health problems) and adherence to antiretroviral treatments.

Note: The findings presented here are excerpted from a report prepared by JSI Research and Training Institute, Inc. for the Massachusetts Department of Public Health HIV/AIDS Bureau titled *"*HIV Care Quality and Clinical Outcomes, in Massachusetts' Regional ACT Now Centers, *Part I: Short-term Outcomes of Clinical Care (1999-2000)"* (Version 4, 10/2/02).

Table 8.3 summarizes the demographic data for the ACT Now sample of clients and compares it to the HIV/AIDS surveillance data. Table 8.4 presents clinical information on these clients.

Table 8.3 Demographic Characteristics of a Sample of Clients Served by ACT Now[1] in 2000 Compared to Demographics of People Living with HIV/AIDS in MA

	2000 ACT Now Clients (Sample)		PLWH/A[2]	
Gender:	%		N	%
Male	63%		10,121	71%
Female	37%		4,039	29%
Place of Birth:	%		N	%
US/US Dependency	79%		11,898	84%
Non-US	21%		2,262	16%
Race/Ethnicity:	%		N	%
White (not Latino)	44%		6,686	47%
Black (not Latino)	25%		3,756	27%
Hispanic/Latino	29%		3,461	24%
Asian/Asian American	2%		158	1%
Native American/Aleut/Eskimo	0%		18	<1%
Other/Unknown	1%		81	1%
Exposure Mode[4]:	%		N	%
Male-to-male sex (MSM)	*23%*		4,582	32%
Injection Drug Use (IDU)	*41%*		4,397	31%
MSM/IDU	--		463	3%
Heterosexual Sex	*51%*		1,925	14%
Other[3]	*4%*		220	2%
Presumed Heterosexual Sex	--		1,914	14%
No Identified Risk	*2%*		659	5%
TOTAL	**998**		**14,160**	

[1] AIDS Care and Treatment Now (ACT Now) are clinical sites for HIV/AIDS specialty care
[2] As of July 1, 2003, reported to the Department of Public Health HIV/AIDS Surveillance Program, includes 36 children under age 13 living with AIDS
[3] Other includes pediatric, blood/blood product and occupational exposures
[4] HIV exposure risk at the Act Now sites is categorized as "all that apply" therefore totals add up to more than 100% and caution should be used in comparisons with HIV/AIDS Surveillance data
Data Source: MDPH HIV/AIDS Bureau Office of Research and Evaluation, MDPH HIV/AIDS Surveillance Program (percentages may not add up to 100% due to rounding); Data as of 7/1/03

- Compared to the total population of people living with HIV/AIDS in MA, the sample of ACT Now clients whose charts were reviewed are more likely to be female, more likely to be born outside of the US or US dependencies, more likely to be Hispanic/Latino, and more likely to report injection drug use (IDU) as an HIV exposure risk. Note that 51% of ACT Now clients reported a risk of heterosexual sex, whereas in the HIV/AIDS Surveillance system, only 14% of individuals were

reported with heterosexual sex as the exposure mode, but another 14% with a risk of presumed heterosexual sex.

Note: For interpretation of the category "presumed heterosexual," see note on page 17.

Table 8.4 Clinical Indicators for a Sample of Clients Served by ACTNow[1] in 2000: MA

	2000 Act Now Clients (Sample)
	N=988
First CD4 (at site) <200[1]:	28%
AIDS diagnosis (by CDC criteria)	53%
Substance Abuse:	
Past or current problem	56%
• Active during review year	23%
• History only	33%
None/not documented	42%
Mental Illness:	
Past or current problem	54%
• Active during review year	43%
• History only	11%
None/not documented	46%
Incarcerated (during review period)	5%
Hospitalized (during review period)	16%

1 A CD4 (also known as T-lymphocyte or T-cell) count of less than 200 is one indicator for a diagnosis of AIDS.
Data Source: MDPH HIV/AIDS Bureau Office of Research and Evaluation

- The population of clients served by the ACT Now program have a high prevalence of AIDS diagnoses (50-53% during review period), past or current substance abuse problems (56-57% during review period) and mental illness (50-53%). These factors are indicative of the complexity of needs experienced by the ACT Now clients.

Quality assurance efforts generally aim to meet certain standards or "benchmarks" of care. The benchmarks considered for the ACT Now effort were based on various, nationally recognized sources including the Health Resources Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), and the International AIDS Society (IAS) among others. The following table (Table 8.5) summarizes the results from the Massachusetts ACT Now sites for the parameters selected by the Institute for Healthcare Improvement, which is a program funded by HRSA to assist Ryan White Title III programs in implementing quality improvement initiatives.

Table 8.5 Performance of ACT Now Sites on Institute for Healthcare Improvement (IHI) Standards of Care: MA, 2000

Core Measures for the IHI Standards of Care			
Category	Measure	Goal	ACT Now Sites 2000
Access & Retention	Percent of patients with visit(s) in last 3 months	85%	85% (in last 4 months)
CD4 Count	Percent of patients with CD4 count <200	25% decline	13% decline (1999 vs. 2000)
Viral Load	Percent of patients with undetectable viral load	60%	All pts: 51% at last measure; 60% sometime during year ART pts: 59% at last measure; 70% sometime during year
Clinical Care	Percent of patients on HAART[1]	75%	Of ART-"indicated" by guidelines: 89% ever, 80% at last visit
Self-Management & Adherence Support	Percent of HAART[1] patients with adherence counseling/intervention at their last visit	75%	98% during the year had adherence addressed
Additional Quality of Care Measures			
Category	Measure	Goal	ACT Now Sites 2000
Viral Load (VL)	Percent of patients receiving VL tests in the past 3 months	100%	72% (in last 4 months)
Clinical Care	Percent with hospitalizations	<10%	16% in past year (including psychiatric & substance abuse treatment)
	Percent of patients receiving hepatitis B & C screening	90%	HBV 96% HCV 92%
Prevention	Percent of patients receiving PPD	95%	41% had PPD placed (36% had it read)
	Percent of patients receiving Pap smear in past 6 months	95%	60% had Pap smear or colposcopy during year
	Percent of (eligible) patients with PCP prophylaxis	95%	96%
	Percent of patients receiving pneumovax	95%	82%
	Percent of patients receiving risk reduction counseling	N/A[2]	63% had some risk reduction counseling including: 51% on entry to care 44% in review period

[1] HAART – Highly Active Antiretroviral Therapy (sometimes also referred to as "ART")
[2] Risk reduction counseling is an HIV/AIDS Bureau standard of care measure (and not an IHI standard as are all other standards listed) and does not have a set goal
Data Source: MDPH HIV/AIDS Bureau Office of Research and Evaluation

- The MDPH ACT Now sites in 2000 met or exceeded Institute for Healthcare Improvement standards of care goals in the categories of access and retention, viral load (rates of suppression), clinical care (use of HAART), self management and adherence support, and screening for Hepatitis B and C.
- Given that the Regional Centers of Excellence serve a population with a fairly advanced stage of HIV disease and high levels of co-morbidity, the goals set by the HIV/AIDS Bureau for healthcare quality are very high. Areas where improvement efforts are underway are include viral load testing, screening for Tuberculosis (PPD) and cervical cancer (Pap smears), PCP prophylaxis and provision of pneumovax.

Conclusions*

This report represents a "baseline" (or pre-intervention) assessment for many of the ACT Now sites upon which quality management activities have been planned or undertaken. The findings described here are based on data collected by chart reviews for a range of clinical sites, and so are limited by variations in documentation, chart organization and extractor interpretation. Measures to minimize these variations through improvements to standardization of data recording practices will increase the degree to which the data are useful and reliable for quality assurance activities over time.

Despite the limitations of the data, overall care patterns demonstrated high levels of quality, particularly considering the complexity of needs in the population. Use of antiretroviral therapy was extremely high and consistent attention was paid to treatment adherence. Viral suppression rates observed were similar to rates noted in published literature. However, prevention practices were less consistent. Areas for potential improvement include risk reduction counseling, hepatitis screening and tuberculin skin testing. Finally, certain patient groups who were not benefiting from available treatments were seen at all sites. This will be the focus of the next stage of analysis so as to inform additional quality improvement activities.

* These findings are excerpted from a report prepared by JSI Research and Training Institute, Inc. for the Massachusetts Department of Public Health HIV/AIDS Bureau titled *"*HIV Care Quality and Clinical Outcomes, in Massachusetts' Regional ACTNow Centers, *Part I: Short-term Outcomes of Clinical Care (1999-2000)"* (Version 4, 10/2/02).

Section 2. Support Services

There are three primary sources of data to describe utilization of HIV/AIDS-related support services. The Massachusetts Department of Public Health (MDPH) and Boston Public Health Commission (BPHC) each maintain data on Ryan White Care Act (federal funds) and state-funded clients who receive publicly-funded services through their respective programs. In addition, a consumer needs assessment, performed in Spring

2003 by MDPH and BPHC through a sub-contract with Suffolk University, provides data on 466 interviews with consumers who utilize MDPH and BPHC-funded services.

A. Ryan White Care Act (Title I and II) and State funded services

There are 10,515 consumers of HIV-related support services funded under the Ryan White Care Act (Title I and II) and the Massachusetts state government. The programs are managed by the Massachusetts Department of Public Health (MDPH) and the Boston Public Health Commission (BPHC) through sub-contracts to community based organizations, clinics and human service agencies. De-identified service utilization data from both funding sources were matched in order to de-duplicate the total client pool and determine the total number of individuals receiving services. Of the 10,515 individuals, 5,037 are served by BPHC, 7,933 are served by MDPH, and 2,455 are served by both programs (Diagram 8.4).

Diagram 8.4 People living with HIV/AIDS and receiving support services funded by the Boston Public Health Commission (BPHC) and the Massachusetts Department of Public Health (MDPH) HIV/AIDS Bureau in 2002

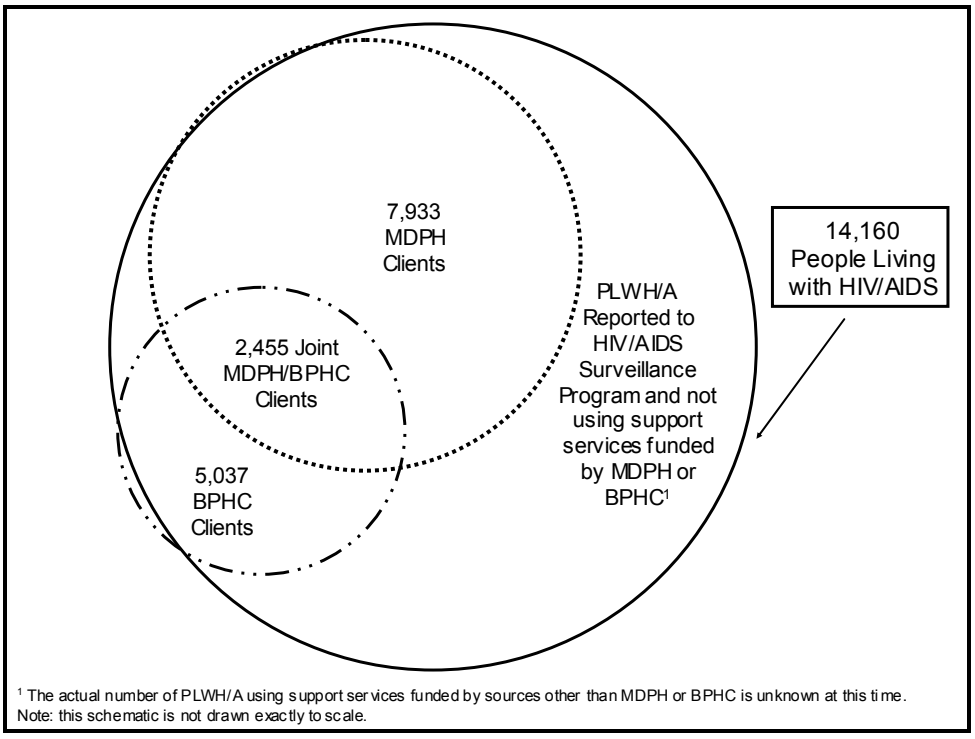


Table 8.6 presents a summary of demographic characteristics of consumers of HIV-related services and compares them to all people reported living with HIV/AIDS in Massachusetts. (Note other demographic categories such as race/ethnicity and place of birth were not included in the first level of analysis of the matched dataset and are therefore not presented here.)

Table 8.6 Comparison of Demographic Characteristics of People Who Received Non-Clinical HIV Support Services in 2002[1] and People Living with HIV/AIDS as of July 1, 2003: MA

	Consumers of Non-Clinical Support Services		PLWH/A	
Gender:	**N**	**%**	**N**	**%**
Male	6,836	65%	10,121	71%
Female	3,636	35%	4,039	29%
Transgender	7	<1%	--[2]	--[2]
Not documented	28	<1%	0	0%
Age:	**N**	**%**	**N**	**%**
Under 13	244	2%	36	<1%
13 to 19	154	1%	58	<1%
20 to 24	141	1%	213	2%
25 to 29	353	3%	559	4%
30 to 34	948	9%	1,508	11%
35 to 39	2,009	19%	2,966	21%
40 to 44	2,481	24%	3,428	24%
45 to 49	2,171	21%	2,698	19%
50+	2,011	19%	2,694	19%
Unknown	3	<1%	0	0%
Health Service Region[3]:				
Boston HSR	3,484	33%	4,607	33%
Central HSR	849	8%	1,228	9%
Metro West HSR	985	9%	1,712	12%
Northeast HSR	1,703	16%	1,977	14%
Southeast HSR	1,526	15%	1,978	14%
Western HSR	1,184	11%	1,636	12%
Unknown	311	3%	9	<1%
Prison[4]	--[4]	--[4]	1,013	7%
TOTAL	**10,515**		**14,160**	

[1]Represents all programs funded by either the Massachusetts Department of Public Health, Boston Public Health Commission or both
[2]category not collected by HIV/AIDS Surveillance Program
[3] HSRs are regions defined geographically to facilitate targeted health service planning. While prisons are not an HSR the prison population is presented separately in this analysis because of its unique service planning needs. Prisons include persons who were diagnosed with HIV/AIDS while in a correctional facility
[4] Incarcerated clients of non-clinical support services are not included here
Data Source: MDPH HIV/AIDS Surveillance Program (percentages may not add up to 100% due to rounding);
Data as of 7/1/03

- During 2002, 10,515 individual consumers received publicly-funded support services primarily consisting of case management, skilled nursing, home health care and/or housing services.
- The demographic distribution of MDPH/BPHC consumers is similar to the demographics of all people living with HIV/AIDS in Massachusetts, although the

percentage of female consumers (35%) is slightly higher than the proportion of females among all people living with HIV/AIDS (29%).

The most commonly used service is case management (80% of all MDPH clients received case management in 2002). Therefore, the demographic characteristics of consumers who use case management are almost identical to all consumers of support services, as shown in Table 8.6. Another important service area provided by the MPDH HIV/AIDS Bureau is housing services. Table 8.7 describes the demographic distribution of consumers who received housing services funded through the Massachusetts Department of Public Health as compared to consumers receiving any type of non-clinical service.

Table 8.7 Comparison of Demographic Characteristics of Consumers Who Received HIV/AIDS Housing Services and all Consumers Who Received Support Services[1,2]: MA, 2002

	Housing Consumers[1]		All Consumers[2]	
Gender:	**N**	**%**	**N**	**%**
Male	522	63%	6,836	65%
Female	311	37%	3,636	35%
Transgender	1	<1%	7	<1%
Unknown	1	<1%	28	<1%
Age:			**N**	**%**
Under 13	5	<1%	244	2%
13 to 19	2	<1%	154	1%
20 to 24	11	1%	141	1%
25 to 29	24	3%	353	3%
30 to 34	61	7%	948	9%
35 to 39	153	18%	2,009	19%
40 to 44	229	27%	2,481	24%
45 to 49	199	24%	2,171	21%
50+	151	18%	2,011	19%
Unknown			3	<1%
Health Service Region:				
Boston HSR	302	36%	3,484	33%
Central HSR	60	7%	849	8%
Metro West HSR	66	7%	985	9%
Northeast HSR	82	10%	1,703	16%
Southeast HSR	106	13%	1,526	15%
Western HSR	118	14%	1,184	11%
Unknown	107	13%	311	3%
TOTAL	**835**		**10,515**	

[1] Includes consumers of MDPH HIV/AIDS Bureau funded programs for housing
[2] Includes consumers of MDPH HIV/AIDS Bureau funded programs for case management, home health, housing and any other non-clinical support service
Data Source: MDPH HIV/AIDS Bureau, Office of Research and Evaluation

- Of the 10,515 consumers who utilize MDPH funded non-clinical support services, 835 utilized housing services.
- Compared to all consumers, those who utilized housing services in 2002 tend to be a little older (69% are age 40 and older compared to 65% of all consumers); they are also more likely to live in the Boston Health Service Region (36% compared to 33% of all consumers).

Table 8.8 presents more detail on the specific services provided in the housing program funded by the Massachusetts Department of Public Health (MDPH) HIV/AIDS Bureau.

Table 8.8 Summary of Services Used by Consumers of Housing Support Service Programs: MA, 2002

Service	N	%[1]
Case Management	587	70%
Housing Assistance	251	30%
Substance Abuse Assessments and Referrals	109	13%
Mental Health	30	4%

Data Source: MDPH HIV/AIDS Bureau, Office of Research and Evaluation
[1] Of all people using support services, there were 835 enrolled in housing support service programs. Percentages represent the number of housing services consumers who used specified services. The total number of services is greater than the total number of consumers because individuals can use more than one service.

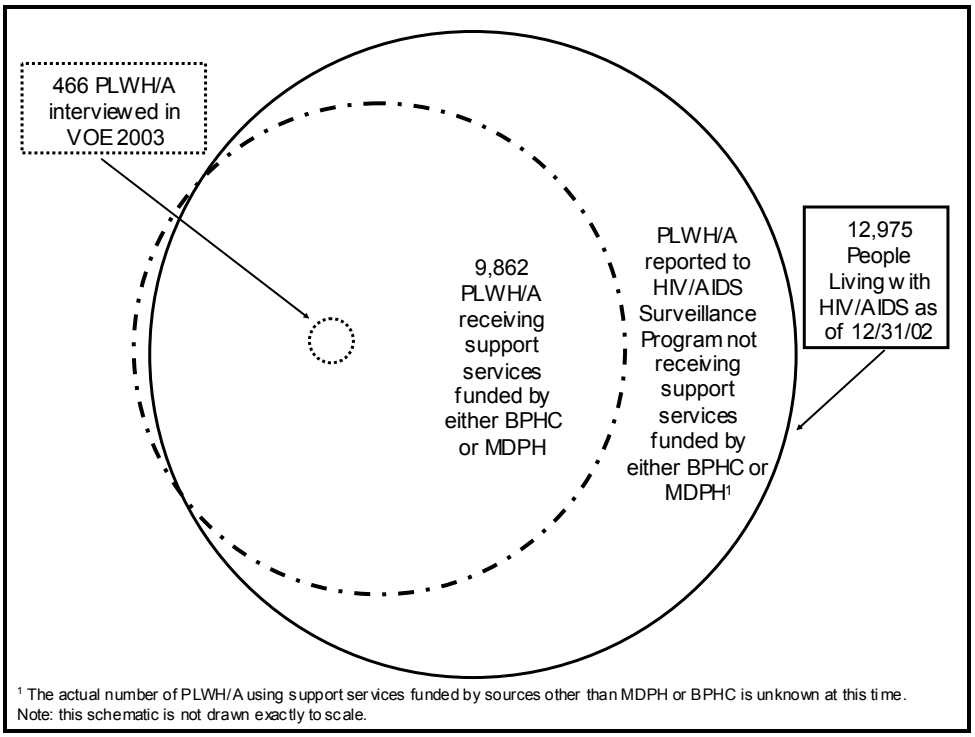
- Of the 835 consumers who utilized MDPH-funded housing services in 2002, 587 (70%) of them utilized housing case management services, 251 (30%) utilized housing assistance services and 109 (13%) utilized substance abuse assessment and referrals services within a state-funded housing facility.

B. Consumer Needs Assessment

The Massachusetts Department of Public Health and the Boston Public Health Commission contracted with Suffolk University to conduct a consumer needs assessment in Spring, 2003 called “Voices of Experience”. The goal of the assessment was to describe consumers’ experiences in accessing and using support services funded by MPDH and BPHC as well as other HIV/AIDS services. The following summary is based on the full report by Suffolk University, *Voices of Experience 2003: HIV/AIDS Consumer Views on Their Needs for Services in Massachusetts and the Boston Eligible Metropolitan Area (EMA)*, which is available online at http://www.state.ma.us/dph/aids/hivaids.htm.
Potential interviewees for the consumer needs assessment were recruited through the mail. A total of 466 surveys were completed by people living with HIV/AIDS.. The majority (77%) of surveys were conducted by interviewers who were also people living

with HIV/AIDS hired as consumer research associates (CRAs). The remaining surveys were completed over the phone (20%) by CRAs or through the mail (3%). When interpreting the findings of the study, the reader should keep in mind that these data do not represent the experience of all people living with HIV/AIDS nor everyone who receives publicly-funded services for HIV/AIDS. All of the data collected for this study were based on self-report. As such there is a possibility that the recall of some information was incomplete or incorrect, or questions were misunderstood, or concerns about comfort or confidentiality inhibited full disclosure.

Diagram 8.5 Sample of consumers who participated in Voices of Experience (VOE) 2003, a statewide needs assessment.



Note: There were 9,862 people living with HIV/AIDS (PLWH/A) and receiving support services funded by either the Boston Public Health Commission (BPHC) or the Massachusetts Department of Public Health and 12,975 PLWH/A reported to the HIV/AIDS Surveillance Program as of 12/31/02. These totals differ from elsewhere in this document where the comparison date is July 1, 2003.

- There were 466 consumers of HIV/AIDS support services who participated in the statewide needs assessment Voices of Experience (VOE) 2003. This represents approximately 5% of all consumers who receive support services funded by the Boston Public Health Commission or the Massachusetts Department of Public Health (HIV/AIDS Bureau).

Demographic Characteristics of Respondents

Table 8.9 describes the geographic distribution of the Voices of Experience sample as compared to MPDH/BPHC consumers and people living with HIV/AIDS.

Table 8.9 Comparison of the Geographic Distribution of Voices of Experience (VOE) 2003 Sample to MDPH/BPHC Consumers and People Living with HIV/AIDS in MA

Health Service Region	VOE 2003 Sample[1]		MPDH/BPHC Unduplicated Consumers[2]		PLWH/A[3]	
	N	**%**	**N**	**%**	**N**	**%**
Boston	193	41%	3,905	40%	4,547	35%
Northeast	79	17%	1,686	17%	1,958	15%
Southeast	65	14%	1,260	13%	1,961	15%
Central	27	6%	659	7%	1,204	9%
Metro west	36	8%	1,123	11%	1,692	13%
Western	39	11%	1,239	13%	1,613	12%
New Hampshire	15	3%	N/A[4]	N/A[4]	N/A	
Total	**466**		**9,862**		**12,975**	

[1] Sample was based on consumers in the DPH and BPHC service delivery system, based on zip code of residence, as of 12/31/02.
[2] There were 2,917 consumers whose zip code did not match a health service region.
[3] Persons Living with HIV/AIDS in MA as of 12/31/02, prisoners excluded. Time frame for people living with HIV/AIDS differs from elsewhere in this epidemiologic profile (7/1/03) to provide most accurate comparison to the target sample and study period for the VOE project; Data Source: HIV/AIDS Surveillance Program, MDPH, Residence is at time of diagnosis and may no longer be current.
[4] While a small part of New Hampshire is in the BPHC catchment area for service provision, clients residing in New Hampshire were not included in this analysis and therefore are not presented here.
N/A= Not Applicable

- The Voices of Experience (VOE) 2003 sample had a slightly higher proportion of females and a similar distribution by race/ethnicity and age compared to people living with HIV/AIDS (data not shown).
- The geographic distribution of the VOE 2003 sample is fairly similar to the target geographic distributions of MDPH/BPHC consumers and people living with HIV/AIDS.
- A slightly lower proportion of the VOE 2003 sample (8%) resides in the Metrowest HSR compared to MDPH/BPHC consumers (11%) and people living with HIV/AIDS (13%).
- Of the 466 people living with HIV/AIDS interviewed for VOE 2003, 63% percent of respondents were male, 36% were female, and 1% were transgender.
- The average age of the VOE sample was 44. Fifty-six percent of respondents were 20-44 and 44% were 45 and older.
- Fifty-two percent of respondents identified themselves as White, 26% Hispanic, and 23% Black.
- More than half of the respondents tested positive 10 or more years ago.
- The VOE consumers reported having very low incomes (90% have annual incomes of $27,000 or less), living alone (47%), living in subsidized housing (58%), and having their healthcare paid for by Medicaid (82%).

Key Findings[1]

- Among HIV/AIDS consumers that we surveyed who receive services in Massachusetts and the Boston Eligible Metropolitan Area (the region in which the Boston Public Health Commission provides services), most accessed primary care in the past year and therefore are not considered to have "unmet need" according to the Federal definition. [2]

  - Ninety-eight percent of the respondents have a primary care doctor or nurse practitioner/physician assistant and 99% have seen their primary medical care (PMC) provider within the last year. The median number of visits in the last year was six.
  - Ninety-seven percent of the respondents have had their viral loads measured and 98% have had their CD-4 counts tested within the last year.
  - Seventy-nine percent of the respondents are currently using antiretroviral therapy (ART).

- While their health needs (including accessing primary care, limiting emergency room use, and taking/adhering to medication plans) were largely met, most consumers had complicated health problems.

  - Forty-six percent have Hepatitis C, 18% have Hepatitis B, 37% report mental illness and 30% report a physical disability.

- Most (84%) HIV/AIDS consumers have case managers.[3] Approximately, one third have two or more case managers. Respondents are evenly divided as to whether they would like to be working with "one" or "more than one" case manager.

- The majority of respondents (53%) reported that they accessed medical services within the first three months of their diagnosis; 17% accessed medical services within 4-12 months of their diagnosis and 30% waited more than a year after their diagnosis. The length of time that respondents waited to seek medical services was similar regardless of whether they were diagnosed a long time ago or more recently.

- Consumers most often reported need for:

[1] These findings are excerpted from the full report by Suffolk University which is available online at http://www.state.ma.us/dph/aids/hivaids.htm)

[2] Consumers were recruited for this study through letters sent to clients of HIV/AIDS service provider agencies and thus by design have had at least some contact with a care giver. The Health Resources Services Administration (HRSA) defines "unmet need" as not having a primary HIV-care visit in a 12-month time period.

[3] Inconsistencies were found in the responses to the "case manager" questions. Several respondents reported not having a case manager but in follow-up questions reported having one or more case managers.

  - case management (86% of respondents)
  - dental care (82% of respondents)
  - food vouchers/food bank (73% of respondents)
  - group or individual peer support (66% of respondents)
  - complementary therapies, such as massage and acupuncture (65% of respondents
  - mental health: individual and group counseling (63% of respondents)

- Of these services, dental care and complementary therapies were also most frequently reported as needed but unattainable because of either a lack of money or insurance, lack of services in the area, or not knowing where to go for the service. (See Table 8.11)

Table 8.11 Services Needed But Couldn't Get and Primary Reason Why

Service	Needed Service But Couldn't Get	Primary Reason(s) Why
Dental Care	25%	Lack of money or insurance to pay for services/medications/ Do not know where to go for services
Complementary Therapies (massage, acupuncture)	20%	Lack of services in my area/ Do not know where to go for services
Housing: Emergency Rental/Utility Assistance	14%	Do not know where to go for services/ Difficulty accessing service providers, providers were not helpful/ Lack of services in my area
Legal and Financial Advocacy	11%	Do not know where to go for services/ Lack of services in my area
Food Vouchers/Food Bank	11%	Do not know where to go for services/ Lack of services in my area
Housing Search and Placement	10%	Lack of services in my area/ Do not know where to go for services
Transportation	9%	Do not know where to go for services/ Difficulty accessing service providers, providers were not helpful
Drug Reimbursement/ ADAP HDAP	6%	Do not know where to go for services
Group or Individual Peer Support	6%	Do not know where to go for services/ Lack of services in my area
Home Delivered Meals	5%	Do not know where to go for services
Mental Health: Individual and Group Counseling	4%	Lack of services in my area
Home Health	4%	Do not know where to go for services
Case Management	3%	Difficulty accessing service providers, providers were not helpful
Respite Care	3%	Do not know where to go for services
Group Meals	3%	Lack of services in my area
Day Care/Child Care	3%	Do not know where to go for services
Primary Care/OB-GYN	2%	Difficulty accessing service providers, providers were not helpful/ Do not know where to go for services
Substance Abuse Treatment	1%	Complicated voice mail and delays/ Told I wasn't eligible for services
Hospice	1%	Do not know where to go for services
Substance Abuse Detoxification	1%	Complicated voice mail and delays/ Told I wasn't eligible for services
Adoption/Foster Care	1%	I have other more important priorities

Current guidelines for primary care of people living with HIV/AIDS include performing a general risk assessment of sexual behaviors and drug use of clients. Consumers reported that many providers did not talk to them about social and behavioral health issues.

- 73% of all interviewed did not talk with any provider about domestic violence, 66% did not talk with anyone about partner counseling and referral of their sexual or needle sharing partner, and 42% did not talk with anyone about disclosure of HIV status.

- 35% of injection drug users or substance abusers did not talk with anyone about counseling and referral of their sexual or needle sharing partner, and 31% with anyone about substance abuse treatment.

- 27% of injection drug users did not talk with anyone about safer drug use.

- Of particular concern, only 79% of doctors talked to consumers who were on anti-retroviral therapies about adherence to medications and 51% about keeping doctor appointments. Case managers and peer support groups were even less likely to talk about these problems.

Conclusions

This study is the "voices" of 466 HIV/AIDS consumers in Massachusetts and southern New Hampshire in Spring/Summer 2003. Many of the consumers who participated in this study have very low incomes, live alone, and are on Medicaid. They have complicated health problems including high rates of Hepatitis C and other chronic and acute illnesses. Most are receiving appropriate levels of medical care and have case managers. However, they are often not getting other services that they have a high need for, such as dental care and complementary therapies, primarily because they do not know where to go for services, a lack of services in their area, or difficulty accessing service providers. Finally, despite current guidelines for primary care, behavioral risk assessment and referral for people living with HIV/AIDS is not a universal practice.